

Article - Health - General

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§13–109.

(a) Subject to the requirements of this section, the Department may adopt rules, regulations, and standards for the detection and management of hereditary and congenital disorders.

(b) (1) Before the Department adopts a rule, regulation, or standard, the Department shall consult:

(i) The public, especially communities and groups who particularly are affected by hereditary and congenital disorders programs;

(ii) Where appropriate, experts in the medical, psychological, ethical, social, and economic effects of programs for the detection and management of hereditary and congenital disorders; and

(iii) The Advisory Council.

(2) Before the Department adopts a rule, regulation, or standard, the Department shall consider:

(i) The incidence of each hereditary or congenital disorder;
and

(ii) The cost of detection and management of each hereditary or congenital disorder.

(c) (1) The rules, regulations, and standards of the Department shall require the Department and each person who conducts a hereditary and congenital disorders program to keep in code and treat as a confidential medical record all information that is gathered in the program and identifies an individual. However, this requirement does not prevent the disclosure of information if the individual or, if the individual is a minor or disabled person, a parent or guardian of the person:

(i) Is informed of the scope of information to be released and the purpose of the release; and

(ii) Consents to the release.

(2) The rules, regulations, and standards of the Department shall provide that, subject to the restrictions on disclosure of confidential information, information on the operation of a hereditary and congenital disorders program shall be open and freely available to the public.

(d) The rules, regulations, and standards of the Department shall provide that procedures for a hereditary and congenital disorders program shall:

- (1) Be accurate;
- (2) Provide maximum information;
- (3) Be set forth clearly; and
- (4) Be reviewed regularly.

(e) The rules, regulations, and standards of the Department shall:

(1) Require that, before an individual participates in a hereditary and congenital disorders program, the person who conducts the program shall inform the individual or, if the individual is a minor or disabled person, a parent or guardian of the person of the requirement that participation in the program be wholly voluntary and of any risk that is involved in participation;

(2) Prohibit the testing of an individual for a hereditary or congenital disorder unless the individual or, if the individual is a minor or disabled person, a parent or guardian of the person:

(i) Is informed fully of the purpose of the test and the nature and consequences of being affected by a hereditary or congenital disorder or being a carrier of a hereditary disorder;

(ii) Is given a reasonable opportunity to object; and

(iii) Does not object to the test; and

(3) Require unambiguous diagnostic results to be made available through a physician or other source of health care to the individual or, if the individual is a minor or disabled person, to a parent or guardian of the person.

(f) The rules, regulations, and standards of the Department shall provide that a hereditary and congenital disorders program may not:

- (1) Require participation in the program;

(2) Require restriction of childbearing; or

(3) Be prerequisite for eligibility for any service or other program.

(g) The rules, regulations, and standards of the Department shall provide that:

(1) Each participant in a hereditary and congenital disorders program shall be:

(i) Protected from undue physical or mental harm; and

(ii) Informed of the nature, cost, benefits, and risks of any therapy or maintenance program available for an individual affected by a hereditary or congenital disorder; and

(2) Each participant in a screening program for a hereditary or congenital disorder shall have available counseling services that:

(i) Are nondirective;

(ii) Emphasize informing the individual; and

(iii) Do not require restriction of childbearing.

(h) Only the Department may adopt rules, regulations, and standards under this subtitle.

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